The EHE Foundation (USA)
The EHE Rare Cancer Charity (UK)
The EHE Rare Cancer Foundation (Australia)
EHE Italia - Non solo Laura
EHE Canada

Quarterly Newsletter for the EHE Group
October - December 2021

the pledge

Edition 27

Just live

Welcome

Contents

Welcome to our 27th edition of **The Pledge,** the quarterly newsletter of the EHE Group, for the fourth quarter, 2021. In this newsletter we include updates on our patient support and advocacy activities, fundraising, and research.

We hope you will enjoy them. In this edition there is also a section on the upcoming EHE360 International EHE Conference organised by The EHE Foundation (see inside for details). As always, we also want to say a huge thank you to all our supporters for their contributions. ***"Just Live".***

Highlights

Wonderful gifts

The Margie and Robert E. Petersen Foundation have provided two more wonderful gifts to help in the fight against EHE, comprising a $1m grant to The EHE Foundation and a $1m additional research grant to Dr Brian Rubin.

The 2022 EHE 360 Conference is very nearly upon us!

The second EHE360 International Conference will be taking place on 28th and 29th January. Registration is now open. Information about the conference can be found on the next two pages.

European EHE research collaboration expands

The EHE Group is delighted to be able to report that two new research projects have been sanctioned. These projects expand on the existing collaboration between INT in Milan and the ICR in London. Details can be found in the Research section of this edition.

Fundraising campaigns a huge success

Q4 saw the culmination of The EHE Foundation's 2021 Fun Run and Walk and their Giving Tuesday matched-funding campaigns. Together these two campaigns raised over $130,000. The UK's matched funding campaign also raised over £20,000 for EHE research.

Tead inhibitor trial to start in early 2022

Ikena Oncology have announced that they will be conducting an exciting clinical trial of their IK-930 Tead inhibitor, and that this trial will be open to EHE patients.

Dr Raj and his team publish IRE ablation paper

Dr Govindarajan Narayanan is one of several authors on a paper summarising the excellent results achieved in using IRE ablation to treat hepatic EHE.

Further details on these stories, and much more, can be found in this edition

the pledge

Edition 27

Just live

2022 EHE 360 International Conference

The second EHE 360 International Conference will be held on January 28th and 29th, 2022. We hope that you will be able join us for this two-day virtual event bringing together researchers, clinicians, patients, and advocates from around the world to advance the fight for treatments and a cure for EHE.

The conference goals:

In our previous edition of The Pledge, we were delighted to be able to report, after the success of the 2021 EHE 360 International Conference, that the 2022 event will take place on January 28th and 29th next year. Each of the two days will have a different audience focus, as follows.

EDUCATION

Increasing knowledge and understanding of key issues central to the diagnosis, treatment, and cure for EHE.

INNOVATION

Providing a novel, catalytic framework to identify gaps and foster dialogue in basic, translational, and clinical research of EHE.

COLLABORATION

Stimulating an interdisciplinary sharing of clinical best practices by strengthening and supporting global collaboration world-wide.

REGISTRATION IS NOW OPEN!

To register go to: https://fightehe.org/2022-ehe-360/ and simply follow the link.

Registration is free, but you must register to receive a required confirmation number, which will be used to enter the event portal on the conference day(s).

Registration must also occur to view the recordings at a later time. The two separate sessions will focus on:

EHE Scientific Symposium *for Researchers & Clinicians*

Friday, January 28th
10:00am to 3:00pm Eastern Time (US)

This is a closed session only for researchers and clinicians to learn about partners' emerging research, share challenges in clinical practice, and guide future basic, translational, and clinical research. Students in relevant fields of study are welcome.

Global EHE Patient Conference *for Patients, Clinicians, Researchers, and Advocates*

Saturday, January 29th
10:00am to 2:00pm Eastern Time (US)

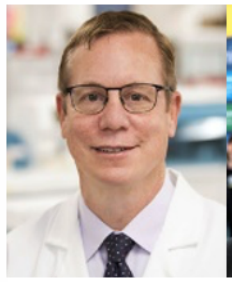
This comprehensive interactive day aims to increase knowledge and understanding of key issues central to the diagnosis, treatment, and management of EHE. It is designed for all patients, whether they are newly diagnosed or have been affected by EHE for a longer period of time. Discussions will be geared towards those familiar with EHE, but with less technical language for those without a medical background.

World-class support from EHE specialists

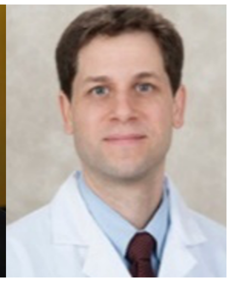
The Foundation is grateful to the Co-Chairs and Presenters (listed below) who have generously given their time to participate in this ground-breaking event. They represent the world's leading EHE researchers and clinicians, collectively working to find a cure for EHE, and will be sharing their EHE knowledge and experience on a wider range of important topics over the two days.

Co-Chairs

- Brian Rubin, MD, PhD (Cleveland Clinic)
- Bill Tap, MD (Memorial Sloan Kettering CC)
- Silvia Stacchiotti, MD (INT Milan)


Brian Rubin
M.D Ph.D.


Silvia Stacchiotti
M.D.


Bill Tap
M.D.

Speakers

- Abha Gupta, MD (Princess Margaret CC)
- Ajay Pobatti, PhD (Cleveland Clinic)
- Andy Donnely (Liver Transplant Patient)
- Aparna Subramaniam, MD (MD Anderson)
- Breelyn Wilky, MD (Uni of Colorado)
- Caleb Seavey, MD (Cleveland Clinic)
- Christina Antonescu, MD (Memorial Sloan Kettering CC)
- Fabio Vanoli, PhD (Memorial Sloan Kettering CC)
- Frank Szulzewsky, PhD (Fred Hutch)
- Fredericus van Eeden, PhD (Bateson Centre)
- Guy Weinberg, MD (Patient Advocate)
- Helen Kouvnadias, PhD (Alfred Health)
- Holly Barker, PhD (WEHI)
- Jeff Ecsedy, PhD (Ikena Oncology)
- John Lamar, PhD (Albany Medical College)
- Katherine Thornton, MD (Memorial Sloan Kettering CC)
- Keith Garcia (Uni of Iowa)
- Munir Tanas, MD (Uni of Iowa)
- Mushriq Al-Jazrawe, PhD (Broad Institute)
- Nadia Zaffaroni, PhD (INT Milan)
- Paul Huang, PhD (Institute of Cancer Research)
- Robin Jones, MD (Royal Marsden Hospital)
- Ryan Kanai (Albany Medical College)
- Scott Okuno, MD (Mayo Clinic)
- Scott Schuetze, MD (Uni of Michigan)
- Smriti Rai, MD (Patient Advocate)
- Tamara Vesel, MD (Tufts University)
- Valerie Kouskoff, PhD (Uni of Manchester)

EHE 360 is organized by The EHE Foundation as part of a patient-led research network, in collaboration with The EHE Rare Cancer Charity UK, The EHE Rare Cancer Foundation Australia, EHE Canada, EHE Italia Non Solo Laura, key global patient advocacy groups, and our medical and industry partners. The EHE Foundation also extends its sincere thank you to our volunteers, and the generous support of our Foundation's initiatives and mission from the Margie and Robert E. Petersen Foundation and the CZI Rare As One Project. Finally, we would like to thank our event sponsors shown below for their wonderful support.

Platinum Level Sponsor:

ikena ONCOLOGY

Silver Level Sponsor:

EVERYLIFE FOUNDATION FOR RARE DISEASES

Bronze Level Sponsor:

Cleveland Clinic

01 Patient Support and Advocacy

The EHE Group's patient support is largely driven by the tireless energy and contribution of so many of our members, most of whom are EHE patients themselves.

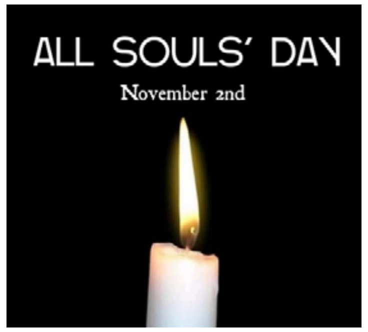
It is this community that continues to warmly welcome and compassionately support anyone diagnosed with EHE, wherever they may live. It is for the EHE community that our EHE foundations work so hard to deliver increased awareness of EHE, while striving to create ever-greater support and connectivity for our members. We thank all our supporters who have contributed to this critical part of our activity, examples of which are provided in this section.

Messages of compassion

The patient support of the global EHE group comes in many forms, and we try to include many of those in every edition of The Pledge. Many are inspiring, some are uplifting, some challenge the community to do more, to not let cancer define them, and to ***Just Live.*** We love all these messages of encouragement and support.


Sometimes we need someone to simply be there...Not to fix anything or do anything in particular, but just to let us feel we are supported and cared about.

But equally, if not more important, are the messages of compassion for our members who are fighting the progressive form of EHE, or who may have suffered a terrible loss of a family member or close friend, or for the family members and friends of a patient who will also be deeply impacted by EHE. The outpouring of compassion and love in these situations may not take away the pain, or negate the sadness, but we know from many posts that these messages of support are very important and do help individuals get through difficult times.



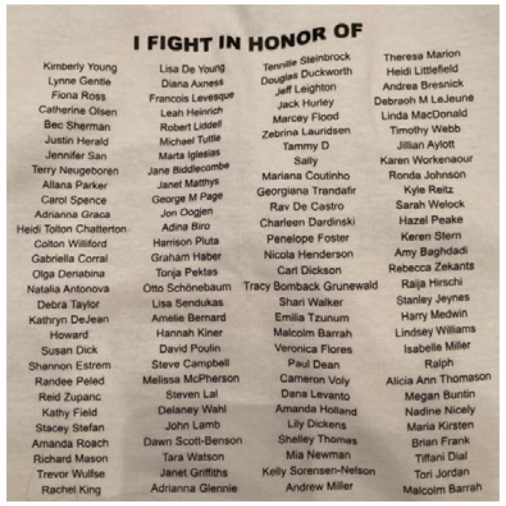
And each quarter we see members post general messages of compassion, and thoughts for those who are no longer with us. Wendy Cassidy included a simple message on the 2nd November that I think we would all agree with.

"The loved ones we have lost always in our thoughts!"

Our community will continue to support EHE patients wherever they are in the world, regardless of race, creed or gender. We will encourage and care for those who are fighting EHE and, as said by Wendy, we will never forget those who are no longer with us physically. The EHE foundations worldwide will carry the fight to EHE through the research they are funding, to bring forward the day when EHE is no longer life-threatening. We will do that in memory and honor of **"the loved ones we have lost".**

"I fight in honor of..."

Last quarter we reported on the success of Kimberly Young's **'Keep Fighting'** t-shirts with their powerful **"I fight in honour of"** design on the back. The original shirt was designed by Kimberly for the Maine Marathon which she ran on 1st October, as reported in the 'Fundraising' section of this newsletter.


I FIGHT IN HONOR OF

Kimberly Young
Lynne Gentle
Fiona Ross
Catherine Olsen
Bec Sherman
Justin Herald
Jennifer San
Terry Neugeboren
Allana Parker
Carol Spence
Adrianna Graca
Heidi Tolton Chatterton
Colton Williford
Gabriella Corral
Olga Deriabina
Natalia Antonova
Debra Taylor
Kathryn DeJean
Howard
Susan Dick
Shannon Estrem
Randee Peled
Reid Zupanc
Kathy Field
Stacey Stefan
Amanda Roach
Richard Mason
Trevor Wulfse
Rachel King

Lisa De Young
Diana Axness
Francois Levesque
Leah Heinrich
Robert Liddell
Michael Tuttle
Marta Iglesias
Jane Biddlecombe
Janet Matthys
George M Page
Jon Oogjen
Adina Biro
Harrison Pluta
Graham Haber
Tonja Pektas
Otto Schönebaum
Lisa Sendukas
Amelie Bernard
Hannah Kiner
David Poulin
Steve Campbell
Melissa McPherson
Steven Lal
Delaney Wahl
John Lamb
Dawn Scott-Benson
Tara Watson
Janet Griffiths
Adrianna Glennie

Tennille Steinbrock
Douglas Duckworth
Jeff Leighton
Jack Hurley
Marcey Flood
Zebrina Lauridsen
Tammy D
Sally
Mariana Coutinho
Georgiana Trandafir
Rav De Castro
Charleen Dardinski
Penelope Foster
Nicola Henderson
Carl Dickson
Tracy Bomback Grunewald
Shari Walker
Emilia Tzunum
Malcolm Barrah
Veronica Flores
Paul Dean
Cameron Voly
Dana Levanto
Amanda Holland
Lily Dickens
Shelley Thomas
Mia Newman
Kelly Sorensen-Nelson
Andrew Miller

Theresa Marion
Heidi Littlefield
Andrea Bresnick
Debraoh M LeJeune
Linda MacDonald
Timothy Webb
Jillian Aylott
Karen Workenaour
Ronda Johnson
Kyle Reitz
Sarah Welock
Hazel Peake
Keren Stern
Amy Baghdadi
Rebecca Zekants
Raija Hirschi
Stanley Jeynes
Harry Medwin
Lindsey Williams
Isabelle Miller
Ralph
Alicia Ann Thomason
Megan Buntin
Nadine Nicely
Maria Kirsten
Brian Frank
Tiffani Dial
Tori Jordan
Malcolm Barrah

The fourth quarter saw more examples of people wearing their t-shirts in honour of loved ones and friends. Here are just a few. We love these shirts. Well done Kimberly for such a brilliant idea.

Wendy Cassidy

"It's arrived ! Allana would have been so proud! Thank you Hugh Leonard, Kimberly Young and all who have donated and purchased a T-Shirt for this terrible disease! Wishing you all a healthy Christmas and New year. My prayers are with you all XX."

Mariana Coutinho

"After my CT scan today, got home... and look what I got in the mail! Just in time for Christmas. This Christmas I am remembering those we lost and thinking of those of us who are still fighting. Merry Christmas EHE family."

Nicola Henderson

"Happy new year everyone! People living with Epithelioid hemangioendothelioma (EHE) sarcoma have a moto - it's to ***'Just Live'.*** With everything going on in the world, and all the uncertainty it's literally all any of us can do, live the life you've been blessed with. It applies to us all!! Life's not a given, it's precious and fragile but oh so amazing. On the back is a list the names of the EHE patients WORLDWIDE. What's so poignant is that some listed are those who have lost their fight with EHE, so we remember them with love and determination to fight on for them. I really hope this pandemic allows more 'living' for us all this year! I plan on doing a lot of that! LOVE YOU ALL, CHEERS TO 2022."

01 Patient Support and Advocacy

Perspectives on life openly shared

The EHE Facebook pages are an important part of providing support, care and encouragement to EHE patients globally. With an ultra-rare cancer, Facebook and other social media platforms provide a unique opportunity to connect people worldwide, and give individuals the chance to connect with fellow patients; something that may be impossible to do physically. We know from nearly all our members how important these pages are.

One of the most uplifting aspects of these social media forums is that nearly all the support and encouragement is provided by EHE patients and their families themselves; the very people who understand intimately what living with EHE involves. We particularly love it when members provide a very personal view of what EHE has meant to them, and how their lives have changed. These stories are nearly always inspiring, as we see and hear how people are determined to ***Just Live,*** and not let cancer rule their lives.

A wonderful example, and great contributor to our group, is Carl Dickson, who lives in the US. Carl has been battling EHE for over 20 years now, and continues to post positive and inspiring messages of encouragement. In October he asked us all to recognize the importance of the people and relationships around us; something that can be overlooked in an ever-busier, technology-driven world. As Carl put it:

> “Share real time with a family member, an old friend, or a new friend. Remember, WE DON’T KNOW HOW LONG THE REST OF OUR LIFE WILL BE, SO MAKE THE MOST OF WHAT YOU HAVE NOW, DON’T REGRET IT LATER!”

It’s such an important message, Carl. Thank you for all your words of inspiration, and we loved the family photos, once again ***Just live*** personified!

Just Live Tattoos

Our group’s ***Just Live*** motif has always been a hugely popular tattoo with many variations. Many people find inspiration in ***Just Live*** for different reasons. The tattoos have also been the start of many discussions about EHE with strangers, which helps to spread awareness of this rare sarcoma. It’s always exciting when people share photos of their new ***Just Live*** tattoos in support of a loved one. Stahsha Jaramillo O’Donnell shared a photo this quarter, with a simple message of love:

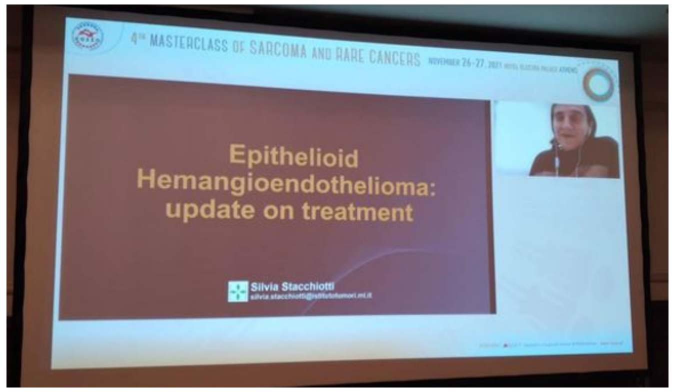
> “I got this done yesterday for my baby girl.”

We love this design, Stahsha and we hope it brings health and happiness to your **“baby girl.”**

Learn more about the ***Just Live*** movement at **https://fightehe.org/just-live/**

Dr Stacchiotti presents in Greece

Jane Gutkovich posted news in late November that Dr Silvia Stacchiotti, from INT in Milan, a key European clinician in the fight against EHE, was presenting specifically about EHE during the 4th Master Class of Sarcoma and Rare Cancers in Greece. We are always excited to see EHE being presented on such occasions, helping to grow awareness of the disease.



Dr Stacchiotti and INT are also playing a key role in the growing EHE research and clinical care initiative in Europe, as detailed in the ‘Research’ section of this edition of The Pledge. We want to thank her and her colleagues at INT once again for their wonderful contribution to the global campaign against EHE.

EHE Facebook page continues to grow

The EHE Facebook page is a core component of the global EHE communication network. This page links hundreds of EHE patients and their supporters globally, providing a unique forum for EHE patients literally anywhere in the world to share information and seek help.

Lisa Hartle de Young published updated numbers at the end of the year:

> “We are 2188 members strong representing 77 countries worldwide. I added 233 new members to our cherished EHE patient-led support group in 2021. I processed nearly 500 membership requests last year (2021), as well as EHE patients who are not on social media. It sure didn't feel that rare.”

Thank you Lisa for your ongoing dedication to the support of the EHE community.

02

EHE Research

Our pipeline of new EHE proposals seeking funding and support continues to provide exciting opportunities for new research to add to our existing EHE research. In this edition of The Pledge we are delighted to be able to report on two new European EHE projects funded by the EHE Group. This leaves us excited by the potential of our research activity to deliver improvements in the care and treatment available for EHE patients everywhere. We hope that you also will find the research articles in this edition both inspiring and exciting.

An exciting new trial of a TEAD Inhibitor

Over the past six years, the EHE Group has funded, and continues to fund, multiple EHE research projects that have many different objectives and deliverables. At the highest level however, all of these projects have a common goal, namely to answer key questions about the biology and natural history of EHE with the hope of identifying a new treatment for EHE that can at least help us to control the disease, and even possibly 'kill' it.

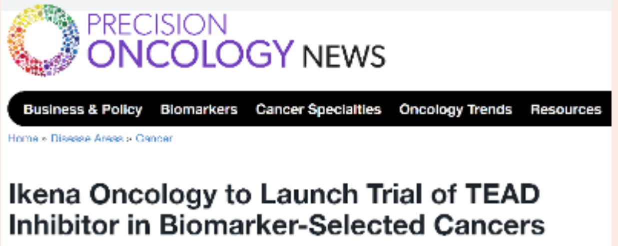
Of all of these objectives, a key focus has been on the role of the TAZ-CAMTA1 fusion protein. EHE occurs due to a chromosomal translocation that yields a WWTR1-CAMTA1 gene fusion that in turn encodes the TAZ-CAMTA1 fusion protein. Fusion proteins that result from chromosomal translocations are particularly good targets because the resulting cancer is typically "addicted" to the mutant protein, in this case, TAZ-CAMTA1. Indeed, the most effective cancer therapies developed to date target disease-driving mutant proteins that are required for cancer formation and growth.

Inhibiting TAZ-CAMTA1 function was therefore seen as a key to treating EHE. This was the focus of Dr Rubin's drug screening research that the EHE Group funded in 2018, to identify compounds that may inhibit the EHE fusion protein. Of particular interest was to see if a means could be found to inhibit TAZ-CAMTA1 from binding to TEAD4, another protein in our cells. This is of particular interest as TAZ-CAMTA1 cannot bind to our DNA on its own, and so needs to bind to TEAD4 before it can influence the transcription process and so drive EHE. Blocking this process could allow us to halt or inhibit EHE progression.

In addition to finding ways to inhibit TEAD binding, another key missing element for EHE was an animal model or cell line of the disease that could allow testing of any such drug or compound. This fundamental requirement was met when Dr Rubin's genetically engineered mice (GEM) finally presented with EHE. Not only did the mice present with EHE, but they presented with EHE that was an extraordinarily strong analogue to human EHE. The ability to test drug impact on EHE was further enhanced this year when INT in Milan were able to confirm that they had successfully created an EHE PDX mouse model. PDX mice have human tissue implanted in them which is then kept alive and grows thanks to the mouse.

So with Dr Rubin's GEM and INT's PDX models, we are now in a very strong position to test new drugs and compounds designed to inhibit TEAD. If successful, then the next step would be a potential clinical trial.

The EHE community were therefore very excited when Jane Gutkovich posted information from Precision Oncology News of just such a trial that was being promoted by Ikena Oncology, and which will be open to EHE patients:

> “Ikena Oncology confirmed that the US Food and Drug Administration has cleared an investigational new drug application for its TEAD inhibitor IK-930, allowing it to begin evaluating the agent in cancer patients harboring genetic mutations in the Hippo signaling pathway.
>
> 
>
>
> Ikena Oncology to Launch Trial of TEAD Inhibitor in Biomarker-Selected Cancers
>
> Boston-based Ikena will therefore be launching a biomarker-guided Phase I trial of IK-930 in tumor types that have a high frequency of Hippo pathway alterations, including NF2-deficient malignant mesothelioma as well as certain soft tissue sarcomas with YAP/TAZ genetic fusions, such as epithelioid hemangioendothelioma. Additionally, Ikena will study the agent in combination with other targeted treatments in patients with solid tumors harboring EGFR and KRAS mutations.
>
> IK-930 blocks TEAD-dependent transcription of genes that cause cancer progression, metastases, and treatment resistance. According to the firm, preclinical research supports further exploring the treatment as a monotherapy and in combination with targeted agents such as EGFR and MEK inhibitors.
>
> "Our biomarker-driven approach will be key in determining which patient populations stand to benefit most from IK-930," Sergio Santillana, Ikena's chief medical officer, said in a statement
>
> Ikena hope to begin the Phase I trial in early 2022.”

It is also exciting that Ikena Oncology requested, and have been given, a slot during the EHE360 International Conference at the end of January at which they will provide further details. The EHE Group will also be liaising closely with Ikena Oncology to understand and communicate timing and procedures for patient involvement in the trial.

02 EHE Research

European collaboration expanding

Initial collaboration:

At the start of 2021, The EHE Rare Cancer Charity (UK) signed agreements and initiated a collaborative research project involving 'The Instituto Nazionale dei Tumori' (INT) in Milan, Italy and 'The Institute of Cancer Research' (ICR) in London, UK. The project, entitled **'The evaluation of cytokines and hormones as biomarkers for EHE'** will last two and a half years and has two key objectives. These are:

1. To assess i) the profiles of circulating cytokines, hormones (and miRNAs), and ii) the ERα, Erβ and GPER expression and the YAP/TAZ activation in tumour tissues, as a function of the clinical course of the disease; and
2. To identify and validate novel biomarkers to inform patient management (prognosticators and predictors of response to medical agents) as well as potential therapeutic targets.

Funding for the project is provided by EHERCC and The EHE Foundation. The European project will also collaborate with Memorial Sloan Kettering (MSK) in New York, USA, but the MSK work is being funded by a private donation in the USA.

Exciting expansion:

In 2021, INT and ICR approached the EHERCC about further EHE research included in two different projects. The projects, summarised below, represent an exciting expansion of the overall EHE research being undertaken. Following positive recommendations from the appropriate Advisory Boards, the grant applications were approved and at the end of the year, verbal commitment had been given and contracting was being finalised.

Project 1:

This expansion of the current collaboration between INT and ICR is a three year project with three key objectives and six overall deliverables:

Objective 1:

The generation and characterization of patient-derived preclinical models of EHE to assess the activity of anticancer agents and identify/validate novel therapeutic targets.

Deliverable 1:

The generation of four or more additional PDX models of EHE from patients with different variants of the disease and characterized by the presence of WWTR1-CAMTA1, YAP1/TFE3 or variant WWTR1 fusions. After confirmation of the consistency with the originating clinical tumors, in terms of histomorphology and presence of disease-specific marker(s), the models will undergo a comprehensive molecular characterization by WES, RNA-seq, and proteomic/phosphoproteomic analysis;

Deliverable 2:

PDX models will be used to assess the activity of drugs relevant for the disease (including but not exclusively sirolimus) as monotherapy and in combination with hormonal therapies such as progestins, aromatase inhibitors and gonadotropin-releasing hormone (GnRH) analogues (for premenopausal patients); pazopanib, interferon, thalidomide, eribulin, taxanes), with the final aim to inform the design of new clinical trials for EHE patients;

Deliverable 3:

generation of EHE cell lines following mechanical disaggregation of PDXs and subsequent FACS sorting of human cells. The availability of PDX-paired cell lines will be instrumental to investigate the cellular and molecular determinants of drug activity;

Deliverable 4:

a CRISPR whole genome screen will be used on PDX-derived cell lines to identify new therapeutic targets for the disease;

Objective 2:

The validation of circulating microRNA (miRNAs) differentially expressed in EHE patients compared to healthy donors.

Deliverable 5:

Circulating miRNAs found to be differentially expressed in plasma samples will be validated and their potential as biomarkers will be defined;

Objective 3:

Radiological features and response assessment.

Deliverable 6:

Collation and review of a comprehensive collection of the radiological assessments performed at the foreseen timepoints by all patients enrolled. Images will be uploaded on a centralized platform and reviewed by a sarcoma dedicated radiologist. INT will create an imaging data hub for this project using the XNAT platform. Evaluation of the imagery will be used to try and gain greater definition of radiological progression and the assessment of treatment response in EHE which remain major challenges. The appearance or worsening of serosal effusion, the changes in serosal involvement, and the limited increase in size over a short-time interval in slow-growing variants are not promptly captured by Response Evaluation Criteria for Solid Tumor (RECIST) definition for disease progression. This makes the use of such criteria unsatisfactory in this complex disease and could potentially lead to a delay in progression recognition and treatment start.

FONDAZIONE IRCCS
ISTITUTO NAZIONALE
DEI TUMORI

ICR The Institute of
Cancer Research

Hugh Leonard commented:

> **"This proposal, covering three different areas with multiple deliverables, represents a significant expansion in the EHE research that the EHE Group is driving. We hope that the results will help answer key questions, as well as validating further research in each of the areas that are being looked at. We are also pleased that the collaboration does not just apply to the research, as the project is again being jointly funded by the EHERCC and The EHE Foundation."**

Project 2:

The second project, funded by EHERCC, involves the setting up of an observational prospective EHE patient registry in Europe. This project will be managed and coordinated by INT in Milan, but will involve four additional institutions in Europe. The resultant five participants at the start will be:

1. Fondazione IRCCS Istituto Nazionale Tumori (INT) (Milan, Italy)
2. Institute of Cancer Research (ICR) / Royal Marsden Hospital (London, UK)
3. Centre Léon Bérard Cancer Center (Lyon, France), at the Medical Oncology Department
4. Universitario Vall d'Hebron (Barcelona, Spain)
5. Maria Sklodowska-Curie Institute-Oncology Center (Warsaw, Poland)

This study initially plans to include approximately 100 patients (range: 80-120), over 36 months, (with a minimum of 2-year follow up for every patient) and then potentially extended. The study aims to provide a description of the population affected by EHE, giving an insight into the natural history of the disease and its variants, identifying reliable clinical prognostic and predictive factors, and analyzing the broad spectrum of treatment approaches and subsequent outcomes, and so allowing us to answer some of the outstanding questions on its management.

02 EHE Research

Kate Hooper, trustee of the EHERCC, commented:

> “This is an exciting development in our battle against EHE. We have talked for some time about setting up a prospective registry. This will also be easier and potentially more successful now that the driving force, namely Dr Stacchiotti and INT, is coming from within the European sarcoma clinical community. We also hope that once established, we may be able to enrol additional European countries into the registry, and provide it as a possible registry model for other areas of the world. We could not be more grateful to INT for all that they are doing and contributing to the fight against EHE.”

We know that the teams at EHERCC and The EHE Foundation are excited about these two new projects which they hope will go live early in 2022. We certainly look forward to providing further exciting updates in the future. Finally, everybody at The Pledge also wants to thank the teams at INT and ICR for their ongoing interest and dedication to EHE research.

Biobanks need your support

As we approach the end of the year, one of the achievements that both The EHE Foundation in the USA and The EHE Rare Cancer Charity in the UK are proud of is the progress of their respective EHE biobanks.

In the UK, the National EHE Biobank is based at the Royal Marsden Hospital, Hugh Leonard explained:

> “The National EHE Biobank went live in Q2 here in the UK. Since then we have had 13 people enrol. We hope more will follow because the more people we can get to enrol the more samples we will have which will make a difference to future research possibilities. So we would love everybody who can, and is prepared to, to enrol with the EHE Biobank.”

In the USA, the EHE Biobank is based at the Cleveland Clinic. Jenni Case Kovach also wanted to encourage support for the biobank:

> “It’s just over one year since we launched the US based EHE Biobank? For such a rare cancer, we have had success so far in collecting samples! Thank you, as every EHE patient who chooses to participate in tissue donation is directly helping our efforts to further EHE research! It's also very important for all patients to know that donating tissue does NOT affect, change or interrupt your treatment or medical care. Patients donate extra tissue or fluids taken as part of your regularly scheduled treatment or procedure. This is a win-win, as biobanks strategically provide donated tissue/fluids as a resource to the whole research community, not just within one institution or to one researcher.”

In Australia, EHE tissue has been banked since 2018 within the existing biobanking process established under the WEHI Stafford Fox Rare Cancer Research Program. Jonathan Granek, Director of The EHE Rare Cancer Foundation Australia, commented:

> “We looked at both setting up a dedicated EHE biobank as well as evaluating existing options. Australia was lucky as the world-class WEHI Stafford Fox Rare Cancer Research Program already had a biobanking capability which EHE patients could participate in. So that was a ‘no-brainer’ for us. We were just delighted to be able to join an established process.”

You can learn more about these EHE biobanks on the websites of the EHE foundations, or by simply reaching out to the appropriate biobank coordinator as listed below if you want to discuss your participation and the donation of your samples to the biobank. Hugh Leonard summarised the situation:

> “If you are having a procedure that will result in the removal of fluids or tissue associated with EHE, or even just giving bloods at a regular consultation, and if you want your samples to help research, then please contact the appropriate biobank or foundation personnel. They will help you with the donation process which is really quite easy. But if you do nothing, some of your samples may be destroyed or lost, and those retained will be simply stored with no easy way to ultimately connect them to EHE research. Remember, your samples can provide huge research benefits, but we have to capture them first.”

Many of our patients do understand the fundamental importance of supporting the biobank. One such example was Chris and Cheryl Cotton. Even on the morning of Cheryl’s loss, Cheryl wanted to promote the importance of biobanking:

> “With the greatest sadness I lost my husband this morning to EHE. His short but difficult battle only lasted 29 weeks from being fit and well with just a niggly bad back to losing him, but he managed to successfully donate samples of his hip to the EHE biobank. As an academic, the knowledge that Chris had helped by making this donation gave him comfort. Thank you for all the support and information this group offered us during this difficult time.”

We send our deepest sympathies to Cheryl and all Chris’s family, but at the same time say a huge **“thank you”** to them for their support of the biobank and EHE research, even during such a difficult period.

For those who are interested, here are the relevant contacts for those who can help you with the EHE biobanking process:

In the USA:

1. Contact Patty Cogswell, EHE Biobank Coordinator, on **1-919-619-1811**, or at **Biobank@fightEHE.org**; or
2. Visit the EHE Foundation biobanking page at: **https://fightehe.org/ehe-biobank/**

In the UK:

1. Contact the EHE Tissue Coordinator at the National UK EHE Biobank at the Royal Marsden Hospital, at **EHEbiobank@rmh.nhs.uk**; or
2. Hugh Leonard at the EHE Rare Cancer Charity (UK) at **hleonard@ehercc.co.uk**; or
3. Visit the EHERCC biobanking page at: **https://www.ehercc.org.uk/national-ehe-biobank-uk**

In Australia:

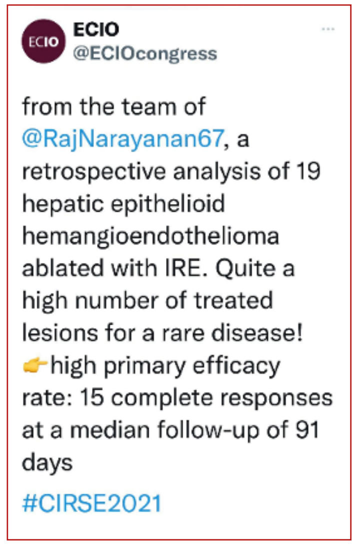
1. Contact the EHE Rare Cancer Foundation Australia (EHE-RCFA): **info@ehefoundation.com.au** if you have any queries regarding participating in the WEHI Stafford Fox Rare Cancer Research Program, or to notify the foundation of a recent/upcoming surgical procedure.

02 EHE Research

Focus is on IRE Ablation

In recent years, a small number of EHE patients have had their liver tumours treated using IRE Ablation. The first such case was in Australia, but since then by far the greatest majority of cases have been in the USA, and a majority of these procedures were performed by Dr Govindarajan Narayanan. Results have been typically positive, with high rates of efficacy, suggesting that IRE ablation should be a potential 'go-to' procedure for treatment of hepatic EHE.

However, in many parts of the world, IRE treatment is not recognised nor approved as a treatment modality for hepatic EHE. This means that IRE ablation is not available under national health care systems nor typically covered by medical insurance. To change this situation, the existing EHE cases that have been treated using IRE ablation needed to be collated, analysed and the results presented, to provide support for the application of IRE for hepatic EHE.



ECIO
@ECIOcongress

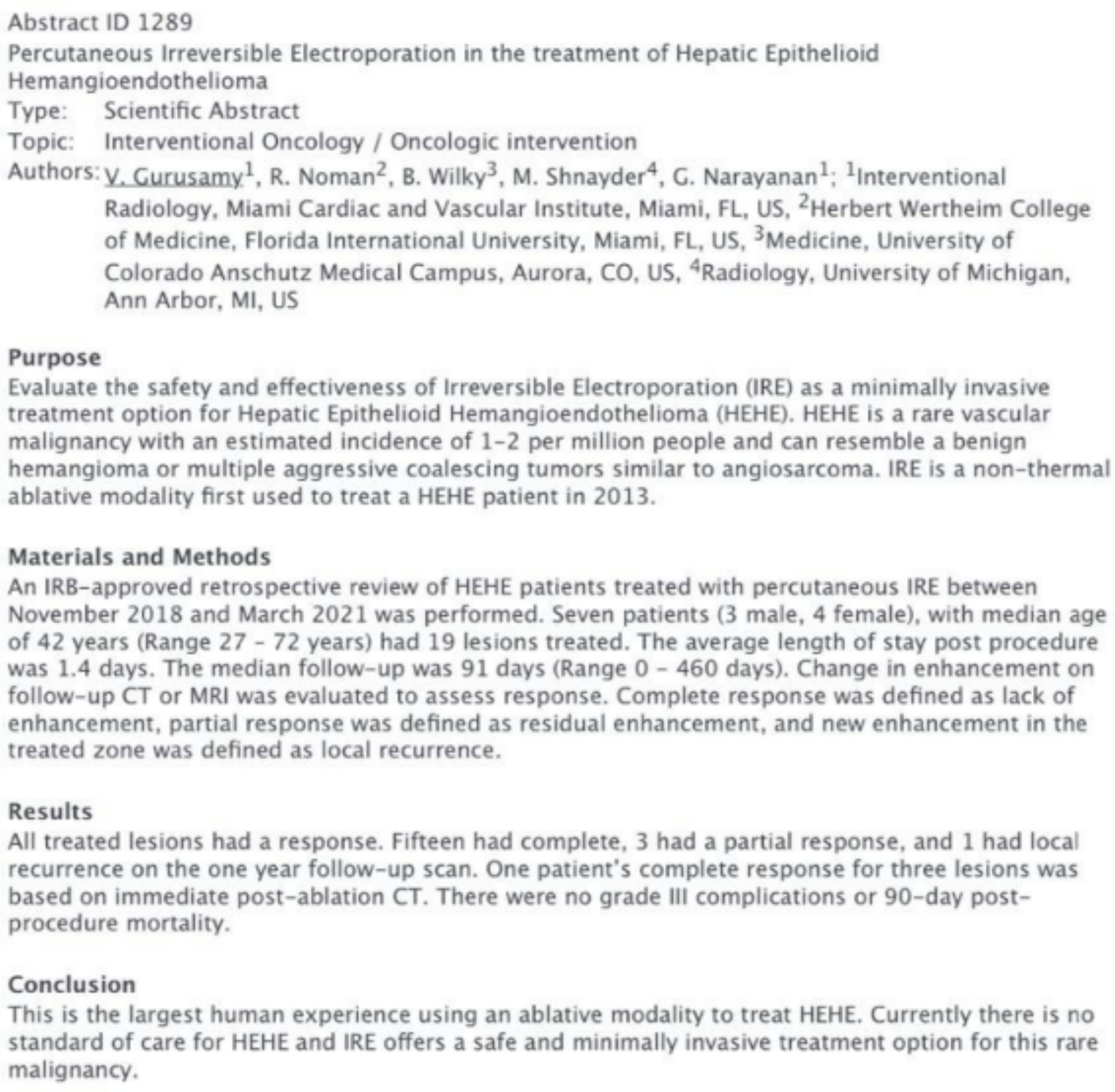
from the team of @RajNarayanan67, a retrospective analysis of 19 hepatic epithelioid hemangioendothelioma ablated with IRE. Quite a high number of treated lesions for a rare disease!
👉high primary efficacy rate: 15 complete responses at a median follow-up of 91 days
#CIRSE2021

The EHE Group were therefore delighted to see a post from Dr Narayanan in October confirming that just such a paper had been produced and accepted by the Cardiovascular and Interventional Radiological Society of Europe (CIRSE) for their 2021 Summit. The paper had also been highlighted through the European Conference on Interventional Oncology (ECIO) Congress twitter feed.

Hugh Leonard explained:

> “We have been striving for some time to get the appropriate specialists from the field of interventional radiology to produce a paper to support the use of IRE in the treatment of hepatic EHE, as we have seen such positive results from many of our EHE members. This paper is a wonderful starting point and will provide us with the catalyst for accessing clinical experience and support for the use of IRE in the treatment of EHE here in Europe, and hopefully its approval as a treatment available under the different European national health systems. I am sure that there will be more hurdles to jump over, but hopefully this paper is the starting gun!”

We have provided a copy of the abstract of the paper here, and look forward to updating the EHE community in the future on further positive developments.



Abstract ID 1289
Percutaneous Irreversible Electroporation in the treatment of Hepatic Epithelioid Hemangioendothelioma
Type: Scientific Abstract
Topic: Interventional Oncology / Oncologic intervention
Authors: V. Gurusamy[1], R. Noman[2], B. Wilky[3], M. Shnayder[4], G. Narayanan[1]; [1]Interventional Radiology, Miami Cardiac and Vascular Institute, Miami, FL, US, [2]Herbert Wertheim College of Medicine, Florida International University, Miami, FL, US, [3]Medicine, University of Colorado Anschutz Medical Campus, Aurora, CO, US, [4]Radiology, University of Michigan, Ann Arbor, MI, US

Purpose
Evaluate the safety and effectiveness of Irreversible Electroporation (IRE) as a minimally invasive treatment option for Hepatic Epithelioid Hemangioendothelioma (HEHE). HEHE is a rare vascular malignancy with an estimated incidence of 1-2 per million people and can resemble a benign hemangioma or multiple aggressive coalescing tumors similar to angiosarcoma. IRE is a non-thermal ablative modality first used to treat a HEHE patient in 2013.

Materials and Methods
An IRB-approved retrospective review of HEHE patients treated with percutaneous IRE between November 2018 and March 2021 was performed. Seven patients (3 male, 4 female), with median age of 42 years (Range 27 - 72 years) had 19 lesions treated. The average length of stay post procedure was 1.4 days. The median follow-up was 91 days (Range 0 - 460 days). Change in enhancement on follow-up CT or MRI was evaluated to assess response. Complete response was defined as lack of enhancement, partial response was defined as residual enhancement, and new enhancement in the treated zone was defined as local recurrence.

Results
All treated lesions had a response. Fifteen had complete, 3 had a partial response, and 1 had local recurrence on the one year follow-up scan. One patient's complete response for three lesions was based on immediate post-ablation CT. There were no grade III complications or 90-day post-procedure mortality.

Conclusion
This is the largest human experience using an ablative modality to treat HEHE. Currently there is no standard of care for HEHE and IRE offers a safe and minimally invasive treatment option for this rare malignancy.

03 EHE Fundraising

The determination of our EHE fundraisers continues to amaze us, driven by the simple desire to defeat EHE. We hope you find the following articles inspiring. If you do, we encourage you to think about how you might be able to mobilise friends, family and colleagues to help raise the funds we need to ensure we can not only maintain, but also expand our EHE research programmes. Fundraising does not need to involve massive campaigns or extreme sports. It is often the collation of many small sums that adds up to the funding we need.

Another extraordinary gift from the Petersen Foundation

In mid-October, the President of The EHE Foundation, Jenni Kovach, announced a transformational $1M gift from the Margie and Robert E. Petersen Foundation to drive forward progress towards treatments and a cure for Epithelioid Hemangioendothelioma (EHE), a rare vascular cancer. This support provides capacity-building resources and essential funding for important Foundation-led research initiatives and will primarily focus on the first global EHE Patient Registry and the EHE Biobank.

Medha Deoras-Sutliff, Executive Director of The EHE Foundation, said:

> “A private gift of this magnitude is transformational for our Foundation and will greatly intensify EHE research. Our patient-led research efforts are critical to understand the course of EHE and provide information essential to clinicians and researchers. We are so grateful to the Margie and Robert E. Petersen Foundation for their support.”

This builds upon previous gifts in recent years by the Margie and Robert E. Petersen Foundation to The EHE Foundation and Cleveland Clinic. Their funds directly supported EHE research conducted by Brian Rubin, MD, PhD., Chairman of the Robert J. Tomsich Pathology and Laboratory Medicine Institute at Cleveland Clinic. The Petersen Foundation had challenged The EHE Foundation to raise another $1 million over three years, which they matched to further fund EHE research at the Cleveland Clinic. The Petersen Foundation gifted another $1 million in 2021 to continue Dr. Rubin's promising work, in addition to the $1m gift to The EHE Foundation. To date, the Petersen Foundation has given $4 million to fund EHE research.

Jenni Kovach, Board President of The EHE Foundation, and an EHE patient, commented:

> “Our Foundation is 100% committed to finding a cure and supporting EHE patients and families. We are incredibly grateful to the Petersen Foundation for their years of support and funding. This award brings us closer to our goal – a world where EHE is treatable and curable.”

Automobile publishing giant Robert E. Petersen owned magazines such as Motor Trend and Hot Rod Magazine and founded the Petersen Automotive Museum in Los Angeles.

The EHE Foundation's partnership with the Margie and Robert E. Petersen Foundation has allowed the foundation to become a strong, recognized, and fully sustainable organization that stands at the forefront in the fight against rare cancer.

2021 EHE Fun Run and Walk another huge success

The EHE Foundation want to thank their wonderful participants, supporters, and sponsors for making their 2021 EHE Fun Run and Walk a tremendous success! Together, more than 900 supporters across the nation helped raise more than $45,000. Thanks to the backing of their sponsors, every penny brought in for this event will go directly to EHE research.

This annual event does much more than create awareness and funding for EHE research. Each team represents an EHE patient with a very unique story. The EHE Fun Run and Walk allows teams of families, friends, and other supporters to rally together and show their unwavering support for their loved one and other EHE patients. Julie Wahl, Vice President of The EHE Foundation, commented:

> “Year after year, we are amazed at the passion, drive, and dedication of our many supporters who help make the annual EHE Fun Run and Walk an extraordinary success. For many families, it's a time to reflect on the wonderful support system that surrounds us, and to come together in a positive and grateful atmosphere.”

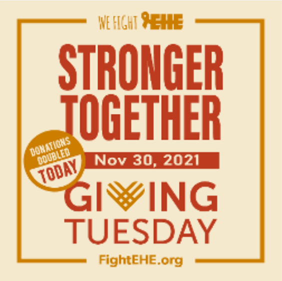
Read the full story and check out the Foundation's sponsors and event photos at **https://fightehe.org/2021-ehe-fun-run-walk-event-huge-success/**

03 EHE Fundraising

Giving Tuesday Matched Funding Campaigns

Each year, following Black Friday, and Cyber Monday, Giving Tuesday represents a global day where people are encouraged to make donations to causes that are important to them. The EHE foundations have enjoyed wonderful support on these occasions, not only from generous individual donations, but from wonderful individuals and companies that have committed to match the funds raised. This has a huge effect, not only doubling funds raised but also encouraging even greater engagement with grass roots fundraisers.

Giving Tuesday donations to The EHE Foundation were matched again this year. Jenni Kovach explained:



> “As the EHE Foundation’s President, I am proud of our Board of Directors for personally matching all donations made on Giving Tuesday. There is so much good stuff going on in EHE research and our volunteer Board is committed not only with their valuable time, but with personal funds. Any donation on Giving Tuesday makes a BIG impact. Thank you!”

Many supporters set up their own fundraising pages, shared posts and emails, or shared their personal EHE story. The EHE Foundation raised a total of $43,000 which was doubled to $86,000 with matched funding, and was quick to post their sincere thanks.

> “THANK YOU! Your donations totalled an amazing $43,518 and our very own Board of Directors here at The EHE Foundation doubled your donations to total $87,036. This total doesn’t include employer matches and Facebook matches. Donors will be notified in early 2022 by Facebook if their donation was further matched.”

In addition to The EHE Foundation Giving Tuesday campaign, the EHE Rare Cancer Charity (UK) also ran a matched funding event. Kate Hooper, trustee of the charity explained:

> “We were delighted to be able to announce that one fantastic donor had again offered to match all funding that the charity raised, up to £10,000. Recognising however that limiting this offer to Giving Tuesday, 30 November only, could be very limiting for a small charity, the donor agreed to extend the offer to include all fundraising completed between the end of November and the end of the year!!”

EHE Rare Cancer Charity

The EHE Rare Cancer Charity's Matched Funding Campaign for Giving Tuesday 2021

The charity was so grateful for this amazingly generous offer. But to benefit from this matching the charity needed to raise those funds, with the chance to raise £20,000 if they could raise £10,000 themselves. The call therefore went out to all the charity’s supporters to seek their assistance, including sharing the campaign as widely as possible.

Once again the charity’s supporters were not found lacking, with funding coming in from multiple sources. So at the end of the year, Hugh Leonard, Chair of Trustees, was able to confirm some great news:

> “You guys, your families and all your brilliant supporters once again stepped up to the plate. You raised £10,000, exactly, thanks to a final top-up donation from Cheryl Cotton in memory of Chris. A special shout out to Kelly for her brilliant pub quiz (£1,075), Hazel (£1,000 donation from work) and Sarah (£1,850 from her annual charity lunch). Our text donations raised £185. The rest came from a stream of generous donations through Just Giving. All in all an amazing effort from you all.”

We have already raised **£10,000** with more events to follow. So that equates to over **£20,000** with matching!

Thank you to everybody who contributed to our Matched-Funding Campaign

While this total achieved the £10,000 target, Hugh was able to confirm that Hazel Peake’s work will be organising a quiz night for her in Derby in January and the charity’s generous sponsor has agreed to include that in their matched funding, taking the total matched well over £10,000. The Charity wants to thank the sponsor, but also every single person who contributed to the multiple fundraising events that were held in support of EHE research.

The Pledge also wants to add its thanks to all those who donated, and all those individuals and companies who offered matched-funding. Our foundations can only achieve what they do because of people like you. **Thank you!**

03 EHE Fundraising

Craft auctions raise funds for research

Fiona Louis, living in Canada, posted news of her latest and final fund raisers for 2021:

> “This is one of the last EHE Fundraisers for this year. Thank you to the lovely ‘crafters’ who donated. I got so many items I will have two auctions. The first one is mostly handmade gnomes and shawls. If you like handcrafted unique items or know others who do please consider shopping. You do need to register to bid. I would appreciate you sharing too.”

Interest was huge and the two auctions raised $1,400 in total. Congratulations to Fiona for another great event.

Another great charity lunch

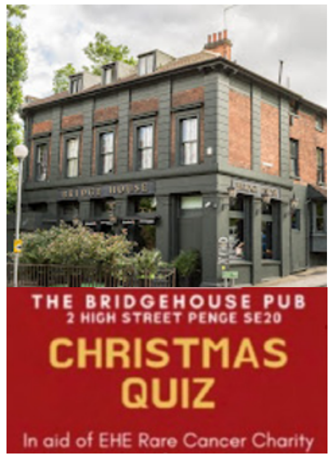
At the end of 2019, Charlie Medwin and two friends rowed the Atlantic in support of Charlie’s brother, Harry, who has EHE. Sarah Medwin, Charlie and Harry’s mother, also wanted to help raise funds and at the same time support Charlie in his amazing challenge.

So Sarah held her first EHE charity lunch. Brilliantly supported by a great group of friends, the event was a huge success. Sarah then decided she would hold an EHE charity lunch annually, not knowing that the 2020 event would be lost to COVID restrictions. So when December 2021 came around, Sarah and her friends once again set about organising a special lunch event to raise money for EHE research. Sarah explained:

> “It was an amazing event. Sadly about 20 people could not attend due to COVID, but they all still paid for their ‘lunch’ which was tremendous, and we still had over 30 who took part. Lots of people contributed with the result that we had a wonderful three course lunch with wine. Starting with mini quiches and pork bites, we then moved on to main courses which included Turkey and 2 hams, lasagne, roast potatoes and lots of salads, and finished with profiteroles, trifle, and 25 individual puddings. I cannot thank people enough for their amazing generosity and support!.”

Special thanks go to all those who contributed, including Janet Waring, Sarah’s brother, Amanda Redfern, The Clipper (a local café), Katrina Drummond, Heather Crawford, Sarah’s Mum, Debbie Coyles and Sue Davey; and all those who brought drink, made donations and generally had a great time. Together this fantastic group raised £1,850 in support of Sarah’s son Harry and EHE research, and when added to the matched funding campaign, their total rose to £3,700. Well done guys. A brilliant effort!

EHE Quiz night asks lots of questions



Kelly and her friends have already raised substantial funds for EHE research, but Kelly wanted to do more. So when her local pub, The Bridge House Pub in Penge, offered to host an EHE Quiz Night in December, Kelly was very grateful and super excited.

Planning was soon in full swing. The pub sold tickets at £5 each, and local media outlet, **Community Magazine SE20**, sent details to 4,000 local addresses. Kelly organised a raffle and organised her best sales team to sell raffle tickets on the night. Kelly was thrilled:

> “It was a great night, the place was rammed and we had a ball, and raised lots of money for EHE research which was wonderful. I want to thank the Bridge House for doing this for us, and of course everybody who came along and made the evening so special and donated so much!! Special thanks have to go to Belinda O’Grady for her organisation, and to Kamil and Gurdeep for selling the raffle tickets. Thank you everybody for making the evening so special!”

Kelly’s quiz raised £1,075 on the night which with the charity’s matched funding campaign rose to £2,150. We also want to thank Kelly and everybody on the night for their unbelievable support.

Kimberly Tackles Marathon to Honor Those with EHE

As she laced up and prepared to run the **Maine Marathon** virtually, Kimberly Young was reminded of how fortunate she was to be doing so because so many of those who have fought or are currently fighting this cancer are unable to do so. She dedicated her run to them.

On October 1st as Kimberly finished her marathon, she tried to describe what she was feeling:

> “Pride, disbelief, a whole lot of fatigue, but mostly gratitude. My family and I are so incredibly lucky to have so many supportive, kind-hearted, selfless people in our lives. I am blown away. I did it. It got so hard. I couldn’t have done it without all of you.”

Many people were there along her marathon route to provide cheers, honks, laughs, and so much support.

Her marathon journey started with her shirt design. She filled the back with EHE names and originally intended to primarily wear her ***Just Live*** shirt for her marathon. Then, many supporters showed an interest in purchasing a shirt, so she organized a shirt sale. Kimberly was able to raise awareness of EHE, secure funds for EHE research, and support all patients worldwide who are battling the disease on two fronts: selling shirts and running a marathon. Her shirts raised over $1,400 in North America, with further funds raised in Europe and Australia.

Kimberly’s story was covered by the Press Herald, giving EHE yet more exposure and helping to raise awareness in the community. You can read the story at:

03 EHE Fundraising

https://wgme.com/news/local/lisbon-woman-with-rare-cancer-runs-maine-marathon-day-early-and-for-a-good-cause?fbclid=IwAR3vc7IPEONXXix1COi-Hdx9-dER4SEmoovAaaC-M7HAcjctXMx1avrqmK4

We are also excited to announce that The EHE Foundation is now a charity bib partner for the Maine Marathon 2022, which means those who register and run the marathon can raise money for EHE research. Stay tuned for details.

We love the t-shirts Kimberly, we love the exposure for EHE, and we love the dedication that took you through the 26 miles on your own.

You are a super star!

Hazel Peake gets wonderful support

Hazel Peake received her EHE diagnosis in late 2021, and like all our EHE members, her life was turned upside down. But like many of our members, this is often followed by amazing and uplifting support. Hazel has seen such support from her wonderful colleagues at Rolls-Royce, in Derby, and the Rolls-Royce Nuclear Power Branch of her trade union, Unite. Hazel explained:

> **“As soon as my branch of Unite heard that the EHE Rare Cancer Charity had launched a matched-funding campaign in December, they stepped up with an immediate £1,000 donation. I was so grateful for this wonderful gesture. Everybody has been so kind. And work are also organising a quiz night for the charity in February, and the funds we raise there will also be matched, so that is tremendous too.”**

We also want to send huge thanks to Unite and to all Hazel’s colleagues. And of course we send Hazel our very best wishes for her EHE treatment. ***Just Live!***

Facebook Fundraisers Continue to Make Incredible Impact

We are thrilled to share that 51 individual Facebook fundraisers took place just this past quarter! The EHE Foundation (US) has a very active presence and a strong community on Facebook and many supporters find its fundraiser feature an easy way to create awareness and help raise money in support of our mission. We can’t thank you enough for sharing our¬ mission and for the generous donations by your family members, friends, neighbors, classmates, co-workers, etc.

Most supporters set up a fundraiser to celebrate a loved one, a birthday, or other special event. Rather than receiving gifts, supporters ask family and friends to donate to their fundraiser to support their local EHE foundation.

Andrea Cohen Bresnick, of the United States, started a Facebook fundraiser for her birthday and shared:

> **“I’ve organized a birthday fundraiser for the EHE Foundation for the past two years. The Foundation’s work is vital to those of us in the EHE community; patients, family members and friends all affected by this rare vascular sarcoma. The Foundation is vital not only for the incredible work it does raising funds for research to find effective treatments and a cure for EHE, but also for increasing awareness about this disease and advocating on behalf of EHE patients. The Foundation serves as a liaison between researchers, patients and health care providers. We all remain hopeful that this work will lead directly to improved patient outcomes while providing hope for patients and their families globally. My network of friends and family generously participated in the birthday fundraiser, and donating the proceeds to the Foundation is the best birthday present.”**

We know you have a lot of options when it comes to donating and we are grateful for every single one of you for your confidence and support. Together, we are making a difference in the fight against EHE.

Half marathons and bike rides back on

The UK were delighted to be able to report that after a COVID-lapse in 2020 and 2021, two of the key fundraising events in the annual calendar are back on in 2022.

The first of these is the **London Landmarks Half Marathon,** an event that was cancelled in 2020 but did take place in 2021. Once again the support from the EHE community has been great with all forty places filled in quick time. This includes two runners from the USA, Denise Robinson and Ann Campbell, who are planning to visit London and run in the half marathon while in the UK. Hugh Leonard, Chair of Trustees of the EHE Rare Cancer Charity (UK) commented:

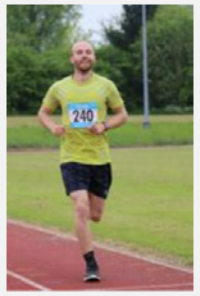
> **“It is so inspiring to see so many people put their hands up and say – “yes, I’ll run for EHE research!” It is hard to express how grateful we are for their brilliant support. And having Denise and Ann here representing the international reach of our EHE Group will also be very special.”**

The second major event is the **RideLondon100,** a major cyclothon over 100 miles, starting and finishing in Central London. Jeff Collins, trustee of the UK charity explained:

> **“This event was cancelled in both 2020 and 2021, but is back on for 2022, which is great. We have secured 20 places in this event, and already have people expressing interest. This year it will be run over a different route which several people have said will make it exciting. We hope they all have a great ride. We used some photos from the 2019 event to get people fired up, and it seems to have worked.”**

In some special cases, we see individuals who go even further, taking on both events. A great example of this is Paul Dean, who joined the EHE community in 2021. Part of Paul’s reaction to his EHE diagnosis has been to engage in fitness and a better diet. Paul explained:

> **“Oh one more thing! I’m running the London Landmarks Half Marathon in April as well as riding the 100 mile cycle that Hugh has organised. I’m aiming to do the half marathon in sub 1 hour 40 and complete the cycle before it goes dark!”**



We want to thank everybody who has said they will run or cycle for EHE research. The dedication you show and effort you all put in is inspiring. Without you we would not be able to achieve what we do. **So a huge THANK YOU for your brilliant support.**

04 And in other news…

Every quarter, people will post stories or short messages that are not necessarily related to EHE. We always include a small selection of these as we think it supports the spirit of so many of our EHE community, namely that they will not let EHE control or dictate how they lead their lives. They will ***“Just Live”!*** Here are the posts for this quarter.

A wonderful message

Jonathan Granek posted this excellent photo, capturing a great message. Thanks for sharing that with us Jonathan.

Wonderful photos

As our regular readers will know, we love to include each quarter a collection of the photos that people post, usually with a message of support and encouragement. Carl Dickson, in the USA, is a regular contributor, and this quarter is no different. Thanks Carl for more great photos and messages of support.

> “I wanted to share this semi-EHE color evening sky as I have yet another colorful, chilly, beautiful night in the mountains of Colorado. Hope you like it, especially those of you that cannot get out.”

The EHE Foundation (USA)
www.fightehe.org

The EHE Rare Cancer Charity (UK)
www.ehercc.org.uk

The EHE Rare Cancer Foundation (Australia)
www.ehefoundation.com.au

EHE Italia – Non solo Laura
website not yet available

EHE Canada
website not yet available